Aided Language Stimulation and a Robust Language System: Autism a Case Example

Linda J. Burkhart and Aura Baker

Aura Baker is a dedicated Mom to her two amazing young sons, the eldest of which is on the Autism Spectrum. A former dancer with the New York City Ballet, massage therapist and yoga teacher, she uses her knowledge of the mind/body connection to help support and connect with her sons. Aura chose the road less traveled for supporting son with language, believing in her son and knowing he was deserving access to all language. Along the way she learned lessons from mistakes and triumphs, wading through fears and doubts when her effort seemed invisible, to persist until her son reached a breakthrough and claimed PODD as a voice of his own. She is passionate in sharing that journey in the hopes others will gain the tools to navigate the path to a robust language for children on the Autism Spectrum.

Meet Jax

- Gentle
- Happy
- Resilient
- Desire for learning and connection
- Sensory Processing challenges
- Motor planning challenges
- Difficulties with receptive language understanding
- Autism Spectrum

Building a Relationship

- Have strong presumption of competence, minimal demands and pressure
- Enjoy yourself; have fun!

Communication is not Compliance

- “Communication is the Engine that drives Language” (Martine Smith)
- Communication is never forced
- Emphasis on Naturalistic Approach across all domains – including ABA
Coaching ABA staff to be more naturalistic:
- I taught them by showing them how I play with Jax and the wonderful connection and learning I get from those moments. And then showed them video of themselves playing with Jax “their way” and the ways this was inhibiting his learning
- Jax also showed them by not responding to them unless it was from that emotional connection!
- It’s something I felt important from the beginning and set as a defining line right away at the start

Seeking and selecting a robust aided language system

- Full range of communicative functions
- Agreed upon shared set of symbols and patterns
- Developmental progression - where to go next
- Compatible with Aided-Language Stimulation Implementation Strategies

Vocabulary & Organization for AAC Systems

Like buying clothes for a toddler:
Big enough to grow into (learn), but not so big they trip over it

Goossens’, Crain & Elder (1992)

Need a Robust Language Organizational System that Has Clear Patterns of Organization

This is what led us to PODD (Pragmatic Organization Dynamic Display) Gayle Porter

Features of PODD that reduce load on working memory

- Requires less sophisticated motor skill
- Systematizes presentation of vocabulary
- Reduces random presentation of symbols that have to be consciously processed as new, each time

PODD (Pragmatic Organization Dynamic Display) Gayle Porter, Melbourne, Australia
• Uses recognition memory - reducing load on recall memory

* Has many scaffolds that support early language development
  * Pragmatic branches before relying on syntax for intent
  * Tense markers for early word forms
  * Yes/no intonation marker for early questions
  * Plus many others

• Natural branching - eliminates meta cognitive process of planning what link to follow

* Patterns that continue and build across increasing levels of language and access methods

In Any Robust Language System:
By Systematizing How Vocabulary is Presented, the Child Can Recognize a Pattern and Focus on Communicating Instead of Searching

High Tech

* Speech Output
  * The allure of an iPad is strong
  * Everyone thinks it will be great
  * “Independence” - (Output vs. Outcome)
High Tech

- Screens change very quickly (may make it harder to learn patterns)
- Demands accuracy of fine motor pointing
- Hard to model at an early level and make it sound right
- Voice output is great and something to work towards
- Loved sounds but more like a toy

High tech vs. Light tech:
- the biggest reason is that I could say more with the light tech with less navigation
- High tech: too large a room for error — Jax was only tapping (not isolating a finger) all the time at first
- it moved to fast and if he made an error he would get frustrated

Light Tech

- Smart-Partner Operating System. Human Partners can:
  - Use contextual cues (I, me, my, mine)
  - Provide extra processing time before changing levels in a Dynamic Display
  - Focus on personal interaction vs. technology
  - Interpret approximations and non-verbal cues
  - Far more opportunities for meaningful modeling throughout the day

Peers with 'light' and 'high' tech

- Peers see iPad as a toy as opposed to communication
- Peers are more curious about the book
- Peers are able to say more with a ‘smart partner’ an as a ‘smart partner’
- Ipad doesn’t always sound “right” to them (no smart partner)

Independence vs Autonomy

- Child’s autonomy of message is most important
- “Voice” is not defined by being spoken, it is defined by where it originates and if it matches the individual’s thought
- Learning a language takes time
- Outcome vs Output

Jax’s PODD

- PODD book - direct access
- 16 items on a page - Expanded functions
- Added sensory page
The Strategy: Aided Language Stimulation

• Teach AAC the same way children learn language
• Immersion
• Models of receptive language throughout the day
• Model what matters

Modeling Receptive Langage vs. Mand Model

• Difference in the definition of “Model”
• Model general receptive input in natural situations without any expectations that the child will respond at that moment
• Different from a Mand Model

Tips for Modeling

• keep your energy positive, encouraging, enthusiastic
• Model genuine messages without demanding a response

Tips for Modeling

• Follow his lead
• Encouraging pauses without pressure
• Slow down, pause
• Talk about what matters to the child
• Model in meaningful natural contexts

See Jax Video #1
http://lindaburkhart.com/index.php/handout_jax_autism

See Jax Video #2
http://lindaburkhart.com/index.php/handout_jax_autism
Attention?
When things are new to kids on the spectrum, this is potentially very hard for their nervous system. This is true with anything new: a new PODD, a new page of page PODD, a new person, a new game... much less the newness and stress in an assessment meant to quantify their “ability”. Attention to PODD changes as it becomes less uncertain and less new. And this only happens by lots of diverse modeling. That means modeling when it’s still “new”. Which means modeling when he’s moving, walking away, not looking, etc. It’s all a step in the process.

What does attention to modeling look like?
- Varies day to day
- Often increased anxiety of unfamiliar new language
- More comfortable in familiar contexts

What does attention to modeling look like?
- Attention is with peripheral vision, glances, in short bursts
- Child may not appear to be attending
- Processing and responses may be very delayed

Early Evidence
- Attention to modeling with no pressure
- Responding to modeled messages: “Let’s go home” and “Let’s go in the car”
- Bringing the PODD to Mom and gesturing for her to use it
- Pointed to “more”

See Jax Video #3
http://lindaburkhart.com/index.php/handout_jax_autism

See Jax Video #4
http://lindaburkhart.com/index.php/handout_jax_autism
Set Back

• Early expressive use was so exciting that everyone started focusing more on getting him to express, than to continue the receptive language learning process

• ABA therapists started tracking expression and writing programs around expressing specific words

Doubts, Fears

• Modeled for months and it “looks” like not enough is happening

• Small successes - mostly development of receptive language understanding - but wanting more expressive

• Receptive language learning is a slow process

• Professionals voicing doubts

• Feels hard

AAC Evaluation Requested

• Competent, caring individual

• Conventional testing not possible

• ‘Catch 22’ of Assessing Language, before providing opportunity to learn language

• Traditionally kids have to “prove” their readiness - but all kids are ready for us to talk to them

• No way to accurately capture the competence and ability of kids like Jax

AAC Evaluation Results

• 4 message voice-output device

• Modeling limited (24 word) core board

• No mention of continuing his current language system, until pressed to add by family

Back on Track

• Shock: “I couldn’t bare or tolerate the thought of him only having 4 things to say and thinking this was all he was capable of!”

• Recommendations didn’t allow us to talk to him, like we currently were, to enhance receptive understanding

• 2 weeks after Jax’s assessment he started using his PODD more expressively. Imagine if we had followed assessment recommendations?

• “I love you” and “I’m sorry”

Aura’s letter to the team

Hi All,
Most of us have seen the wonderful increase in Jax’s attention and interest in his PODD. I wanted to share with you something wonderful, and a message for us to remember. Apologies this is long. I hope you will read it.

Jax often gives me hugs, kisses... real deep, connected expressions of love. I’m always grateful for these. I have been able to integrate talking with his PODD to say: turn the page! I LOVE YOU. (I love you icon is on the second page). There was one time where it just clicked for him. He had given me a hug and I modelled “I think you’re saying, I LOVE YOU”. He watched me model it, said “go”, I said “I LOVE YOU” again and gave him a hug. He looked at me intently, moved closer and snuggled. I said yes: YOU/ turn the page/I LOVE YOU. He tracked my finger with his eyes the whole time. I touched “I LOVE YOU” again and gave him a snuggle. Then I just said with my voice, I LOVE YOU while he was looking right at me.
After this moment, that meaning became embedded for Jax. Since then, he has touched a few times, "I LOVE YOU" to me. Which is amazing. But what is also wonderful is he will now understand when someone says it to him. Do we get this?? That means, that if any of YOU love Jax — you can tell him and he will understand on every level and it will mean something deep to him. I can touch "I LOVE YOU" when he’s upset. He looks right at me. He gets it.

I’ve had the same thing happen with "I’M SORRY". He has internalized what this in his language means. This meant that when Baxter hit him with the hula hoop on the head and Jax was upset, Baxter was able to say to him, "I’M SORRY/ "I LOVE YOU". and Jax understood. He new he was respected, loved and important.

The key elements in these moments:
- I was modeling naturally, as opportunity and language arose (like a natural conversation)
- He had a robust system so I could follow our interaction and say anything
- I was following his lead
- There was an emotional, relationship based connection

The outcomes:
- he can say "I love you", and "I'm sorry" to anyone, anytime
- he can receptively understand when someone says it to him (in spite of his audio processing challenges)
- this means he can be emotionally connecting with LOVE and EMPATHY; anytime, with anyone. This is not requesting. This is not compliance. This is life changing communication. This is humanity and connection.

I think to myself… How grateful I am he has a robust language system. How would we know what language he would gravitate towards, what language would come up spontaneously and just "click" like that... to be forever connected with communication? How can we suppose to have the power to decide what language he "gets", "will understand", "use" and "deserves" if he has any language system less than a robust one? And wow, how powerful and important is the foundation of receptive language well before any expectation of expressive.

The message is…

Let's choose to never limit our Jax. He needs our respectful, loving, thoughtful help. Let's make wise choices to encourage him. Let's give him all possibilities. Let's keep our focus on a broad, diverse modeling of receptive understanding for Jax. If we encounter a challenge with his language, then it is up to us to find strategies to problem solve... not to take away words. There is a responsibility in all of our hands, it's important and life changing.

Thanks for listening. Always listen to him too. And every kid you work with. They say so much in any way and every way they can.

With Care,
Aura

Lessons Learned

• Communication is messy
  • Ups and downs
  • Interruptions
  • Imperfections
• The best solution?
  • Model more!
  • Develop habits

See Jax Video #5
http://lindaburkhart.com/index.php/handout_jax_autism

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Lessons Learned

• Focus on quality of modeling across all meaningful areas
• Focus on receptive language
• Keep it no pressure, no testing

See Jax Video #6
http://lindaburkhart.com/index.php/handout_jax_autism

Lessons Learned

• It’s easy to get anxious and “over push” for expression when you want it so bad
• Keep it natural
• Use what is known about typical language development and apply it to AAC system

Advice for Others:

• Drop the timeline and what if’s and when’s
• Expressive use and Receptive understanding will come
• Acknowledge that progress happens at different times for different kids; especially when sensory differences are present
• Try not to compare
• If you give up, then it will never happen

Expressive Language

• Had to be patient and persistent with the slow process to expressive communication
• Jax started with slaps/taps to the book
• As comprehension grew, he slowly refined his ability to point

See Jax Video #7
http://lindaburkhart.com/index.php/handout_jax_autism
Expressive Language

• Respond to anything he indicated
• Talk less, pause more
• Scaffold when needed, but don’t jump in too soon - It is his message

See Jax Video #8
http://lindaburkhart.com/index.php/handout_jax_autism

Expressive Language

• Jax often figured it out himself if I waited, but sometimes walked away - if I waited too long (or if he didn’t have something to say) That is ok!

Peers and Siblings

• Peers are naturally interested in PODD - they really gravitate to it
• Great way to include Jax in school and community
• Peers view Jax as an equal, valuable to the community, interesting, competent with a robust language system vs a limited device with only 4 things to say
• Peers now advocating for Jax’s use of PODD “Jax need his PODD to say goodbye”

Teaching Peers and Siblings

• Use PODD to talk to Peers and Siblings as well as Jax about all kinds of things
• PODD ensures that conversations around Jax include Jax – peer/sibling doesn’t end up talking to you about Jax

See Jax Video #9
http://lindaburkhart.com/index.php/handout_jax_autism
Teaching Peers and Siblings

- Suggest to the peer/sibling to use the PODD for things they just said with speech (with no pressure)
- Incidental learning through using PODD: language and literacy

See Jax Video #10
http://lindaburkhart.com/index.php/handout_jax_autism

Team Building

- Team brainstorming and development of an action plan so everyone is on the same page
- Group emails, texts, shared language journal
- Teach others to model by baby steps: start with saying things from the first 2 pages and then build one pattern at a time
- Let the book guide you as to what you can say and eventually you will be able to say what you want to say

Learning

- Need to develop shared belief that PODD is a language and should be learned as a language, not a task
- It is okay to make mistakes, to fumble, for Jax to walk away this time
- No demands or pressure for expression
- It's like learning a second language

Advice on Facing Challenges

- Minimal support from autism community and professionals
  - Build your own support system
  - Teach one person that will teach others
  - Share videos as teaching
  - Invite them into the PODD

Advice on Facing Challenges

- Professionals may feel overwhelmed when looking at a PODD the first time - too much!
- Some think they know what PODD is from experience with other AAC systems
- May not understand the depth of scaffolds for early communicators in this robust language organization system
- May not understand the approach of aided language stimulation
- May not feel that they need training
Advice on Facing Challenges

• Working with ABA specialists to support naturalistic, child led Language approach
• Dropping ‘mand’ data for language learning
• Adapting data so its naturalistic, not just words
• PODD is communication not compliance
  * Modelling defiance
  * Honoring all communication
  * Following his lead

Hello All,

I so wish I had been able to be here with you today. I poured so much of my heart and precious time into this presentation. Linda, thank you being the leader you are and for being a presence for both of us today. I have no doubt you said things much clearer than I could’ve! I’m also pretty sure I wrote a way too long letter, but I hope you’ll read it anyway.

I had truly wanted to be able to speak to you all in person, so I could look you in the eye and convey to you the very important position you are in. You have the possibility to change lives, to create connections, to offer a doorway to communication. Or you can take away connection, harm lives and close the door to communication. It seems like it'd be an easy choice, wouldn’t it?

My son was failed by professionals I trusted, that had his best interests in mind. We weren’t given the support we needed, we floundered and when we doubted and sought help, his specialist decided he was not worthy of words after all. He simply couldn’t handle it. They were wrong. He was listening all along. He was learning all along. You must realize these choices you make on behalf of these children have serious consequences. These are their lives. It’s not just some test, an assessment, a box to check. They are larger than any paper can quantify. Please don’t abandon them, don’t give up on them — think bigger, be creative, be the one that gives them all the words, all the time. Be the game changers. The movers and shakers. Celebrate the littlest of successes, see them as large signposts you are on the right way. You are!

Imagine if you had a child who was deaf and instead of a hearing aide that let them hear all the words, they were only able to hear select words. Would you expect them to learn language? How would you expect the to be motivated to communicate? What words would you deem important and valuable to teach them first? Jax has significant auditory processing challenges, and while he can technically hear all sounds, that doesn’t equate to him processing those words. His PODD was grounding words and teaching him language all along. We just couldn’t see it yet. How can we ever expect kids to learn language if we don’t offer them ALL the language? If we all say we understand receptive language comes well before expressive language, then let’s truly follow that and focus solely on receptive. Model, model, model. Without pressure, without dependence on expecting expressive language in return.

Learning that Jax’s AAC specialist deemed him only worthy of a 4 choice SGD and a static board was shattering. This is my bright, beautiful, loving, fun, amazing little boy summed up into an awful, dark, bleak assessment that didn’t capture him in the slightest. Imagine how it would feel for him? To know he had only proven his worth to be a handful of words? To know that he was being measured not on the totality of who he is, but on who he is under the most stressful of moments? What a blow to his self esteem, to his intelligence and his potential. How could he ever be motivated to learn to communicate with AAC? These assessments are harming children every day.

It’s worth it!!!!!!
Thankfully, the assessment became a blessing in disguise because it strengthened my resolve and reaffirmed my belief in Jax’s competence, in the slow but eventual process and in his ability. I couldn’t tolerate or bare the thought of him with any less words. And I didn’t want anyone working with him who thought he was less than he was. I found myself advocating and fighting for the very language system I was doubting. So that was it, I was all in. Turns out — so was he...

... only 2 weeks later, he started using his PODD expressively in astounding ways. 2 weeks. Take a minute to soak that in. Take a minute to realize how greatly the system in place is failing our kids. Remember that choice I mentioned before? Here it is. You can open the door to communication or you can close it. What will you choose?

The remedy is simple:
1) Offer a robust language system.

2) Talk to children with their AAC just as we would any child. With emotional connection, with care, with fun, with silly affect, emphasis on what they are communicating. Just talk to them. ALL. THE. TIME.

3) Teach everyone to do this, ALL THE TIME. This perhaps, is the hardest part.

That’s it.
It sounds so simple. Why does it feel so scary when you are in it? Why is it so easy to doubt when you don’t see fast results? We want the quick, we want the fast, we want it all now. We compare, we question. But if we really want a lasting voice, an authentic voice, it’s going to take time. And a lot of commitment.

I want to be clear that our path is not perfect. It’s messy with ups and downs. We have bumps in the road like everyone else. There will always be learning left to do for all of us. You don’t just show AAC and voila! All set. All done. This isn’t a fantasy movie, this is reality. We communicate with Jax every day with his PODD, all the time. He is never without it. This doesn’t happen in a vacuum out of nowhere. It’s a journey. It’s a life choice. You have to get over it “being hard” and get into it “being life”.

I ask you to find your strength and resolve to believe in these kids when it counts the most... when they can’t prove it, when everyone doubts, even when you are unsure. This is when it means the most, this is what it’s all about! Lift them up, presume competence. Not for pretend, not just when it’s easy to say... when it’s hardest to say. For real. Presume competence.

Can we say it together? PRESUME COMPETENCE.

These are human beings, they are valuable and they deserve their basic, essential human right to words. There is no readiness. There is nothing to prove. Give them back their self worth; give them their words.

Because what if you don’t? What if you don’t. What if we hadn’t with Jax. Please remember Jax. Remember me. When you are doubting the process — remember when I did, and how very close we came to losing the amazing, life changing communication we’ve gained for Jax. Thank you so much for your time. If I get this chance again, I hope for it to be in person.

Warmly, and always with Hope,
Aura

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